Sleep and Parkinson’s Disease
A Commonly Overlooked Condition Moves to the Forefront

Sleep problems are a fact of life for nearly 80 percent of people with Parkinson’s disease (PD). Yet sleep disorders remain underreported by patients and underdiagnosed by physicians, despite a growing number of effective therapies available to treat them.

Over the last decade, the Parkinson’s medical community has heard the call to recognize the significance of sleep dysfunction, and the negative impact it has had on the lives of patients and caregivers. Besides exposing sufferers to safety risks and diminishing their quality of life, poor sleep often worsens Parkinson’s symptoms and increases the risk of depression.

While disturbed sleep patterns tend to worsen as PD progresses, sleep symptoms also appear in the early stages of the disease. New research suggests that poor nocturnal sleep and longstanding daytime sleepiness may be risk factors for PD.

The fact is if you have PD, you face unique barriers to sufficient sleep that others do not. Some of which may include unpleasant side effects from medications and the occurrence of overnight motor symptoms.

...continued on page 2
Here are the most common life-disrupting sleep disorders among Parkinson’s patients:

- **Insomnia** You wake during the night and have trouble falling asleep again.
- **REM sleep behavior disorder (RBD)** You act out your dreams during the rapid-eye movement, or REM phase of sleep, moving your legs and arms, talking and shouting, and even hitting or punching. RBD can endanger you and your bed partner.
- **Sleep apnea** Your breathing is interrupted while you sleep, most often because the throat is blocked momentarily by the tongue or other tissues. These brief awakenings during the night can cause excessive daytime sleepiness.
- **Daytime sleepiness** This condition may result in a so-called “sleep attack,” a sudden onset of sleep that occurs without warning and may lead to serious accidents.
- **Restless Legs Syndrome (RLS)** You may feel an unpleasant, tingling or creeping sensation in your legs and an urge to move them. This occurs mainly at night.

For better care to take place, patients and physicians must work together to identify sleep-related symptoms and to problem-solve together. This will, in turn, lead to accurate diagnosis and focused treatment planning.

To that end, patients and caregivers should write down a detailed overview of their symptoms and give those notes to their physician. Then, a medication review should follow to determine whether adjustments need to be made. Finally, a consultation with a sleep specialist and an overnight sleep study may be necessary.

With the help of the latest therapies, patients can move past their obstacles to a good night’s rest. At the Parkinson’s Disease and Movement Disorders Center at Northwestern University in Chicago, there is a unique clinic dedicated to the early diagnosis and comprehensive treatment of a wide variety of sleep problems associated with PD and other neurological disorders. The research program brings together specialists in sleep medicine and PD with the goal of ushering in new therapies.

The National Parkinson Foundation is working with Northwestern and other centers to support sleep research and bring this issue to the forefront. By pooling together resources throughout the community and leveraging expertise, we can make real progress toward improving the lives of people with PD and their caregivers.

We can do many things to improve your sleep. And if you sleep better, your Parkinson’s will behave better.

**Sample questions from the Parkinson’s Disease Sleep Scale:**

- **Do you experience numbness or tingling of your arms or legs which wake you from sleep at night?**
- **Do you have painful muscle cramps in your arms or legs while sleeping at night?**
- **On waking, do you experience tremors?**
- **Have you unexpectedly fallen asleep during the day?**

**Talk to your neurologist if you are concerned about your sleep patterns, or call 1-800-4PD-INFO.**

**Author:** Aleksandar Videnovic, MD, MSc

Dr. Aleksandar Videnovic practices at the PD and Movement Disorders Center at NPF’s Center of Excellence at Northwestern University.

Watch Dr. Tanya Simuni answer common sleep questions in a series of online videos.

Visit [www.parkinson.org/library](http://www.parkinson.org/library) and select “Sleep” under Topics.
10 Steps to Better Sleep

If you're having trouble sleeping, you're not alone. More than three-fourths of people with Parkinson's disease report sleep-related symptoms. But getting plenty of deep, restorative sleep is vital to your health and energy level. In addition to getting a sleep evaluation, here are 10 steps you can take to ensure a good night's sleep.

1. Create a serene sleeping area. Keep your bedroom cool, dark and quiet. Replace worn out mattresses and pillows. Don't eat, read or watch TV in bed.

2. Set a sleep schedule. Rise and retire at the same time every day, regardless of sleep difficulties during the night. Limit naps, which can make it harder to fall asleep at night.

3. Don't toss and turn. If you're unable to sleep after 15 minutes, or if you wake up in the middle of the night, get out of bed and do something monotonous such as reading or listening to soft music until sleepiness returns.

4. Review your medications. Prescription drugs can affect your sleep. Write down every drug you take, including over-the-counter ones, and have your doctor evaluate how they may be disrupting your slumber.

5. Cut caffeine, especially late in the day. It's no secret that caffeine is a stimulant. But it's also a diuretic that can prompt frequent trips to the bathroom.

6. Reschedule dinner. Eating large meals too close to bedtime may make it hard to drop off or stay asleep.

7. Stay active. Vigorous physical activity promotes deep sleep. Try to build at least 30 minutes of exercise into your day.

8. Write down your worries. Ongoing psychological and emotional distress can disrupt your sleep. To soothe your nerves, set aside 15 minutes a day to write or think about what's troubling you.

9. Try light therapy. Getting several hours of light exposure each day, particularly natural morning light, may help reset your body's internal clock.

10. Keep a sleep journal. Jot down what you try and how well you sleep. Review after two weeks to see what worked.

To learn more about sleep issues in Parkinson's, visit www.parkinson.org/sleep.

Complementary Therapies Can Help

Some complementary therapies may help improve quality of sleep and ease symptoms in people with PD. Here are the top ones to discuss with your doctor. If you want to pursue a therapy, be sure to see a skilled and qualified practitioner. (For information on licensing, certification and therapies, visit the website of the National Center for Complementary and Alternative Medicine at the National Institutes of Health, www.nccam.nih.gov, or call them at 1-888-644-6226.)

- **Acupuncture.** A procedure that involves the painless insertion of fine needles into various points on the body to treat a wide range of physical and mental conditions. One benefit of this treatment is greater relaxation.

- **Massage.** A targeted touch technique that can relieve anxiety, headaches, muscle stiffness, joint pain and more.

- **Yoga and Meditation.** These stress-reducing practices promote greater calmness and physical relaxation.
NPF has awarded $1 million dollars to investigators pursuing clinical research projects in 2011. The research NPF is funding will help advance the field in three key areas of Parkinson's disease: 1) an advanced biomarker study, 2) a clinical trial to treat memory impairment and 3) a study of the effectiveness of a treatment for sleep apnea in Parkinson's.

“Each of these projects can have an immediate impact on the lives of Parkinson’s disease patients, from a novel approach to developing a new biomarker to treatments for two important non-motor symptoms,” said Joyce Oberdorf, NPF’s President and CEO. “Both sleep issues and cognition are important but often overlooked contributors to the burden of the disease.”

Under the direction of the Clinical and Scientific Advisory Board (CSAB), NPF supports leading-edge research conducted by the top neurological experts at its 43 Centers of Excellence worldwide. These clinical research fund awards will support three novel clinical investigations at Centers of Excellence in the United States and Canada.

NPF funded the following 2011 two-year clinical research grants:

**MRI Biomarkers for Motor and Non-Motor Manifestations of Parkinson’s Disease:** Martin McKeown, MD and Silke Cresswell, MD, Pacific Parkinson’s Research Center, University of British Columbia.

This study will examine 100 volunteers over two years to look at deep structures in the brain; the goal is to develop a biomarker for Parkinson’s. This is novel because, at present, there is no simple way to measure the progression of PD. This study will develop a reliable method to assess overall disease severity. If successful, this sophisticated technique could be replicated at hospitals anywhere.

**Sleep Disordered Breathing and its Impact on Cognitive Performance and Quality of Life in Parkinson’s Disease:** Carlos Singer, MD, Miller School of Medicine, University of Miami.

Poor sleep affects the quality of life for people with PD, but there is also evidence that it may also contribute to decreased cognition. This study of 200 people with Parkinson’s will evaluate the prevalence of sleep disordered breathing (SDB) and, in people with SDB, measure the effect of a positive airway pressure device on cognition in Parkinson’s. Sleep disturbance in PD has a measurable impact on quality of life, and also contributes to trauma and injury associated with reduced vigilance due to fatigue.

**Sleep and Learn with Transcranial Magnetic Stimulation (TMS) in Parkinson’s Disease:** M. Felice Ghilardi, MD, New York University Medical School.

Motor learning involves practicing a task followed by forming a habit—a short-cut in your brain to do a complex motion. Dr. Ghilardi believes that PD’s effects on learning are associated not with learning the steps but with forming the habit; she has found that TMS can stimulate the cells in the brain that form motor habits. This grant will study whether this stimulation, followed by sleep, can help restore motor learning and lead to a new therapy that could be applied to important motor learning such as preventing falls.

NPF’s CSAB strongly supports these projects and believes that they will have a high impact on our understanding of PD as well as make a difference in improving care. Stay tuned for the next issue of the Parkinson Report for more information on NPF-funded research.

For more information about NPF’s research initiatives, visit www.parkinson.org/research.
When is it Time to Talk with Your Doctor about Parkinson’s Disease?

NPF survey reveals people are hesitant to see their doctor when they show symptoms

A recent nationwide survey* conducted by NPF revealed 60 percent of Americans would wait to see their doctor if they were experiencing consistent regular tremors—despite the fact that most of those surveyed (81%) recognized that tremors are an early warning sign of PD.

Although men suffer from Parkinson’s 1.5-2 times more than females, the men surveyed were more likely to adopt a wait and see attitude (61% vs. 55%) and to be less aware of PD’s early warning signs (86% vs. 91%).

“People should get an assessment as soon as they experience symptoms of Parkinson’s disease. Research shows that getting treatment early can make a difference,” says Michael S. Okun, MD, NPF National Medical Director.

The survey revealed only a third of Americans are familiar with five or more of the 10 early warning signs of the disease. The symptoms they were least aware of were: loss of smell, sleeping trouble, dizziness and fainting. Hispanics are more likely than the general population to recognize some of the lesser known warning signs, such as loss of smell (32% vs. 19%) and constipation (23% vs. 11%), but often have trouble finding expert care.

“This survey underscores the need for more education and ongoing research to provide treatment options that slow or stop the disease,” said Joyce Oberdorf, NPF’s President and CEO. “The National Parkinson Foundation is dedicated to supporting research that will lead to earlier diagnosis and a better quality of life for those affected. Clearly, the first step is greater awareness.”

A Test your grasp of Parkinson’s facts and myths by identifying these seven statements as true or false:

1. Parkinson’s can be diagnosed with a blood test.
2. Memory loss and trouble thinking are early warning signs of Parkinson’s.
3. Parkinson’s is untreatable.
4. Environment can have an impact on Parkinson’s.
5. Parkinson’s usually develops later in life.
6. Women are more likely than men to suffer from Parkinson’s.
7. By the year 2030, one billion people on the planet will be over the age of 65.

Check your answers:

*1,007 interviews were completed by telephone in March 2011 with a representative random sample of U.S. residents age 18 and over. GfK/Roper compiled the survey results.

HELPLINE: English/ Español
1.800.4PD.INFO (473-4636)
Get your PD questions answered.
The National Parkinson Foundation offers immediate and free access to experts in the field through the web-based forums on our website (www.parkinson.org). We answer thousands of questions online, and in this issue, we highlight some of the most popular questions recently asked by people living with PD and their families. We invite you to visit us, read the daily posts, and to ask any question that may be on your mind. We appreciate the direct interaction with the Parkinson's disease community, and we look forward to continuing the dialogue.

Q I heard that Parkinson's disease increases my risk of melanoma. Is that true?
A Melanoma is the least common but most dangerous form of skin cancer. But caught and treated early, it has a 95 percent cure rate. Recent studies suggest that Parkinson's disease doubles your risk of melanoma. It's not clear why; nevertheless, researchers don't think that the use of levodopa or dopamine agonists is responsible for the increased risk. For people with PD, the best protection is to see a dermatologist annually, wear sunscreen daily and perform a head-to-toe skin check every month (See Tips for Daily Living on the next page).

Q Is there a delay in diagnosis of Parkinson's disease in African Americans?
A In a recent analysis, investigators from the University of Pennsylvania NPF Center of Excellence looked at the medical records of veterans newly diagnosed with PD at the Philadelphia VA Medical Center. What they discovered was important: African Americans were diagnosed at a later stage and were more likely to underreport disability than whites. The researchers speculate that “underreporting of disability among African Americans may account for later stages of PD diagnosis than whites and that this may begin to explain the mechanisms underlying observed racial disparities in PD.” Since this is a preliminary observation, further research is needed. In the meantime, if you’re African American and have symptoms, talk to your doctor right away.

Q What do patients and families need to know about genetic testing for Parkinson's disease?
A New understandings of health and disease take into account complex interrelationships among genetic factors and environmental exposures. Simply put, your genes load the gun and the environment pulls the trigger. However, it’s important to know that single gene defects, where one faulty gene in a family is responsible for the disease, account for less than 10 percent of all Parkinson's cases. What’s more, PD is probably not one disease, but rather a syndrome of multiple diseases that share common symptoms. Even so, genes play a role in determining who is at risk. If you want to undergo genetic testing for Parkinson's risk, talk to your doctor and seek genetic counseling. A genetic counselor can answer all your questions, explain the benefits and risks, and help you decide if getting tested is the best course for you.

Top Questions and Answers from NPF's “Ask the Doctor” Forum

www.parkinson.org
Has the door swung open for gene therapy in Parkinson’s disease?

A new gene therapy procedure may one day give doctors a better alternative to the use of medications that, while helpful, work to varying degrees in people with PD. In a landmark randomized, double-blind, placebo-controlled clinical trial of 45 people with advanced PD, investigators from multiple centers across the U.S. used a novel technology called gene transfer of glutamic acid decarboxylase, or GAD, to increase levels of the brain chemical GABA, which is depleted in people with PD and results in rigidity, tremors and impaired reflexes. Half the participants were treated with gene therapy, and the others received a sham treatment. After six months, researchers assessed movement in the study participants and found that those who received gene therapy showed a 23 percent improvement in symptoms. In contrast, those who received the sham treatment improved by only 12 percent.

Despite some setbacks in earlier trials of gene therapy in PD, this comparative study seems to have been successful and opened the door to larger studies. We’re very encouraged about gene therapy, because there is tremendous opportunity to advance therapies in patients who have PD and other neurological disorders. We hope that this study will lead scientists to develop and refine techniques that will ultimately help improve the symptoms that matter the most to patients with PD—levodopa resistant symptoms.

Tips for Daily Living: Melanoma

Though Parkinson’s disease may make you a candidate for melanoma—the most lethal type of skin cancer—you can stay safe. Here’s what you need to do:

- **Cover up.** Wear sunscreen, a hat and protective clothes—even on hot days.
- **Avoid the sun between 10 am and 2 pm.** That’s when the sun’s rays are most intense.
- **Check yourself out.** Examine your skin once a month. Look for new and suspicious black spots on your skin and nails.
- **Get screened at least once a year.** See a dermatologist for a full head-to-toe skin examination.
- **Get treated.** If you’re diagnosed with cancer, don’t delay treatment. Melanoma is curable if detected early.
During the last decade, various therapies have been touted as possible cures for Parkinson’s disease. Some of these include stem cell transplants, glutathione infusions and, most recently, chelation therapy. While the idea behind chelation therapy sounds promising—detoxification of bodily heavy metals—there is no scientific evidence proving its effectiveness in the treatment of PD.

Chelation involves the use of a chemical substance, administered intravenously or orally, that binds to metal ions and minerals circulating in the body. This process allows the toxin to be eliminated from the body. The word chelate is derived from a Greek word meaning claw or to grab onto. EDTA (ethylene diamine tetra-acetic acid) chelation therapy is a common treatment for heavy metal poisoning from lead, mercury and others.

For years, proponents of EDTA chelation therapy have proposed this treatment for cardiovascular disease. The theory goes that this process could be used to extract calcium deposits from blood vessel walls. But no studies have demonstrated that this actually happens and there have even been reports of serious side effects. Similarly, EDTA chelation therapy is now being promoted on websites and in doctor’s offices as a treatment for other chronic diseases such as Alzheimer’s and Parkinson’s.

Still, the theory behind using chelation therapy for PD isn’t so far-fetched. It’s true that high iron intake is linked to Parkinson’s disease. Iron seems to accumulate in brain areas—including the substantia nigra—that are part of the neurodegenerative process. Iron contributes to oxidative stress, a situation where cells release harmful molecules known as free-radicals. Oxidative stress may cause degeneration of brains cells that produce dopamine. Additionally, a few animal studies have found that chelation therapy has a protective effect against the development of PD. However, it has yet to be proven that reducing iron in the brain of a patient with PD would be clinically beneficial or have a disease-modifying effect.

At this time, don’t believe claims that any chelation therapy will effectively treat PD. If a practitioner offers to send your blood, urine or hair to an expert in order to demonstrate a link between your condition and heavy metal toxicity, it’s best to decline. In some instances, samples have been sent to unregulated laboratories, then returned with results indicating positive or unlikely scenarios—such as elevations in multiple heavy metals (for example, lead, mercury and arsenic), which is very rare. Furthermore, avoid clinics that charge a fee to perform chelation therapy for PD. Experimental clinical treatments are performed at academic medical centers under IRB-approved research protocols, and offered for free.

If you’re concerned that you might have heavy metal toxicity, see your neurologist for a comprehensive examination, which should include a heavy metal exposure history. A urine sample can be sent to a laboratory to test for the presence of heavy metals. Remember, an experienced neurologist should be able to detect common heavy metal signs such as neuropathy or lines of discoloration across the finger nails (called Mees’ lines). It’s important to know that Parkinsonian symptoms are atypical manifestations of heavy metal toxicity, except in the case of manganese exposure in miners and in welders.

The bottom line: Although the book may not be closed on chelation therapy, studies are needed to give us definitive answers. Until then, people with PD should avoid chelation therapy.
Team Hope: Beth Bjerke’s Grand Hike for a Grand Cause

Four years after a diagnosis of Parkinson’s disease at age 44, Beth Bjerke took on a big challenge in a “grand” way. On April 11th, Bjerke, now 48, crossed the invisible finish line of Bright Angel Trail, a 20-mile hike to the bottom of the Grand Canyon and back again.

The Tucson-resident and mother of two chose to hike the Grand Canyon during Parkinson’s Awareness Month to raise awareness of Young-Onset Parkinson’s disease (YOPD) and the huge toll it takes on families.

“We’re not all alike, but as a family, we live life on a tight rope,” Bjerke explained. “My hope is to find ways to bring together kids who have a parent with Parkinson’s and help them cope.”

To prepare for the backpacking trip, Bjerke focused on setting short-term goals. “The Grand Canyon gave me a reason to get up and get going every day, and not give in to apathy,” she said. “I didn’t want to become depressed.”

To regain her strength and balance, Bjerke worked with a personal trainer. “I went into the gym half-crunched over, like an 80-year-old lady, and came out looking normal again,” she said.

Bjerke’s homegrown hiking team included her husband, her youngest son and his girlfriend, her stepsister and a close friend. Together, they entered the Grand Canyon in a snow flurry and trekked to the bottom, reaching the Colorado River hours later. They continued their four-day journey on foot through unpredictable weather and amazing views. At one point, a painfully swollen toe threatened to sideline Bjerke, but the avid outdoorswoman decided to “cow girl up” and stuffed her purple toe back into her shoe and pressed forward in pursuit of her goal.

Bjerke’s family and friends surpassed her goal of raising $5,000 for the National Parkinson Foundation. “After being diagnosed with PD, so many people say what now? We all start off that way,” she said. “For me, this is what works best; for how long, I don’t know, but I just came out of one of the Seven Natural Wonders of the World.”

Today, Bjerke is taking scuba diving lessons and dreaming of paragliding the Grand Tetons someday. “You can dream,” she said. “It may not be the best time or conditions, but you can still reach for small goals and build on them.”

For more information about starting your own community fundraiser, visit www.parkinson.org/teamhope.
Ball Up for Parkinson’s

Ball Up, LLC has joined forces with the National Parkinson Foundation to launch Ball Up for Parkinson’s, an initiative to help raise awareness of Parkinson’s disease. The effort includes a PSA featuring the Ball Up All-Stars, an informational website and an all-star celebrity streetball game.

The 2011 Ball Up for Parkinson’s campaign is an important collaboration that brings together sports fans, athletes, families and people affected by Parkinson’s disease. It will raise awareness and funds to support NPF’s mission of improving the lives of people with Parkinson’s disease.

In May, the Ball Up for Parkinson’s PSA was aired at halftime of the 1st Annual Celebrity Match in Los Angeles. Cedric “The Entertainer” was on hand to coach the leading men of Hollywood against the Ball Up All Stars.

“We are thrilled that Ball Up has chosen the National Parkinson Foundation as a charitable partner. Ball Up for Parkinson’s will help us raise awareness of this debilitating disease, which is the second most common brain disease after Alzheimer’s,” said Joyce Oberdorf, NPF’s President and CEO. “More than one million Americans suffer from Parkinson’s, and we are here to ensure that they get the treatments, support and care they so desperately need.”

Studies have shown that any type of movement or consistent exercise program is beneficial and proven to help manage the symptoms of Parkinson’s disease, as well as improving flexibility and mobility. This partnership emphasizes the importance of movement and exercise for people with Parkinson’s.

Ball Up CEO Demetrius Spencer added, “We are proud to announce the launch of Ball Up for Parkinson’s. The goal of this initiative is to help raise awareness and funds to fight Parkinson’s and, most importantly, to keep people moving on and off the court!”

Founded in 2009, Ball Up is the leading streetball tour in the nation, featuring the Ball Up All-Stars, which include many of the most celebrated and talented streetball players from around the country. Through its debut of the 2011 Ball Up Season on Fox Sports Net nationwide and tours that span the globe, Ball Up provides the ultimate streetball experience for both fans courtside and viewers at home. Watch Ball Up games on Fox Sports Net.

All proceeds from Ball Up for Parkinson’s benefit the National Parkinson Foundation.

Get Moving This Fall!

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct. 1, 2011</td>
<td>North Park in Pittsburgh, PA</td>
</tr>
<tr>
<td>Oct. 22, 2011</td>
<td>Atlanta Braves Stadium in Rome, GA</td>
</tr>
</tbody>
</table>
Support NPF
Helping Others Pays in So Many Ways

When it comes to supporting our long-term future, the charitable gift annuity (CGA) is one method favored by many of our donors. When you set up a CGA with NPF, we’ll provide you with lifetime payments that remain constant even with a fluctuating stock market. This offers you the opportunity to supplement your retirement income and continue to make a difference.

How a CGA Works

A CGA is a simple contract between you and NPF. You make a donation using cash or marketable securities and we, in turn, pay you a fixed amount for life. With this type of gift, you can feel secure knowing you can count on receiving stable payments for as long as you live.

Your age when the payments begin and the amount of your donation determine the size of your payment. The older you are, the higher your fixed rate. You receive payments for life, and, if you choose, you can have the payments continue for the life of another person. After that, the remaining funds are used to support NPF.

Find Your Gift Annuity Rate!

<table>
<thead>
<tr>
<th>Your Age</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>50</td>
<td>4.8%</td>
</tr>
<tr>
<td>55</td>
<td>5.0%</td>
</tr>
<tr>
<td>60</td>
<td>5.2%</td>
</tr>
<tr>
<td>65</td>
<td>5.5%</td>
</tr>
<tr>
<td>70</td>
<td>5.8%</td>
</tr>
<tr>
<td>75</td>
<td>6.4%</td>
</tr>
<tr>
<td>80</td>
<td>7.2%</td>
</tr>
<tr>
<td>85</td>
<td>8.1%</td>
</tr>
<tr>
<td>90+</td>
<td>9.5%</td>
</tr>
</tbody>
</table>

Contact Claudia Welsh at 305-243-3881 or plannedgiving@parkinson.org to learn more.

For more information, visit www.parkinson.org/plannedgiving.

VISIT NPF’S BOOTH AT AARP’S EXPO

AARP Presents Life@50+ in Los Angeles, CA: Sept. 22 – 24, 2011

Thousands of AARP members and their friends are expected to join us in Los Angeles for celebrations that are part class reunion; part home, travel, health and high-tech expo; part summer concert weekend; and all fun!

Join this group to receive the latest event updates and connect with others who plan on attending.

Registration and complete details about AARP’s National Event and Expo, Life@50+ in Los Angeles, can be found online at www.aarp.org/events or by calling toll free 1-800-883-2784.